International Society for Quality of Life Research

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PRESIDENT'S MESSAGE

Dr. Ivan Barofsky
Baltimore, MD (USA)

At the closing session of this year's ISOQOL Conference I asked attendees to ask themselves; "Did you learn something new and did you meet someone you wanted to work with?" I stated that this should be the minimum you should expect for yourself after attending this meeting, not only to reassure yourself that your time and money was well spent but also that you received that *spiritual* uplifting that happens when you are finally amongst a group of people who are interested in the same issues you are. That was certainly my experience.

There was a lively discussion at the Policy Forum about integrating health-related quality of life (HRQOL) assessments into all phases of a clinical trial, especially Phase I trials. It became clear that studying HRQOL during Phase I trials in some settings was a non-issue while in others was actively avoided. I came away from the discussion feeling a research question had been identified - does doing HRQOL assessments during a Phase I trial make a difference?

It was also announced that a preliminary draft is under discussion within ISOQOL: "**A Declaration of Patient's Rights Concerning their Quality of Life**." The purpose of the statement is to provide an example of what standards patients can expect concerning the quality of life consequences of their health and medical treatment. Please contact me via e-mail (ibarofsk@welchlink.welch.jhu.edu) if you are interested in receiving a copy of the draft **"Declaration."** Your comments concerning its applicability to your setting is requested. Hopefully, it will then be possible to initiate a discussion about such outcome measures, a discussion that can be followed up with a sharing of each other's approach during an "Assemblage of Nations" which hopefully will occur in Amsterdam.

Consistent with the growing impression that ISOQOL needs to pay more attention to the role of *cultural* variables in determining HRQOL outcomes were two papers that I reviewed as posters. I learned from Ali Montazeri's work, for example, that 80% of a sample of the general Iranian population didn't understand what "quality of life" referred to but did understand the phrase "religious quality of life." Julia Fox-Rushby taught me that there are four terms that refer to health in Kenya and I asked myself what I do now with my carefully constructed HRQOL assessment?

I also learned about the growing research on *cross cultural population-based* HRQOL assessments and how important these assessments are becoming for policy formation. Much discussion concerning this topic occurred in the halls and it certainly became clear that the time has come for a more up-front presentation of these topics at ISOQOL.

What impressed me the most was the high quality of the science presented and the Organizing Committee—lead by Diane Fairclough, Carol Moinpour, David Osoba and David Feeny who deserve our praise for this. Each year this gets better and continuing this progress is the challenge to next year's Organizing Committee.

Finally, I leave my greatest praise and appreciation to Sharon Wood-Dauphinee, who for two years kept ISOQOL together and moving forward. Sharon was our President during a major period of growth and development. I would also like to thank many of the others who have been active in the Society, and I hope they remain so, especially since it is the members that will make the Society achieve its goals and objectives.

Be sure your vote counts!
Return your "yea" or "nay" about the enclosed Bylaws to the ISOQOL office by February 5.

Methods Workshops February 5-6, 2001 Hotel Washington Washington, DC

- January 5, 2001 ~ Early registration deadline
- January 5, 2001 ~ Hotel reservation deadline

Two tracks of workshops geared toward helping those in the research community, private industry, managed care companies, third-party payers, policymakers, and statisticians better understand HRQL measurement and interpretation of self-report data. Please contact the ISOQOL office for information or visit the website.

ISOQOL Executive Office
Email: info@isoqol.org;
WEB PAGE: ***www.isoqol.org***

7th ANNUAL ISOQOL RESEARCH CONFERENCE REVIEW ~ October 29-31, 2000

Editor's note: *Based on his experiences with organizing the ISOQOL 1999 meeting in Barcelona, Jordi Alonso shares with us his impressions of the ISOQOL 2000 meeting in Vancouver. David Osoba not only co-chaired the Scientific Program Committee of the ISOQOL 2000 meeting, he also hosted the meeting as Vancouver is his home town. In this 'diary', he provides 'back stage' information regarding the planning and organization of the conference and also describes how he has experienced the meeting itself.*

Gaining Perspective: the ISOQOL 2000 Meeting in Vancouver

Dr. Jordi Alonso
Barcelona, Spain

I wonder why in a clearly squared designed downtown such as that of Vancouver I had so many difficulties getting oriented. Every time I went out the hotel and started to walk to the South, I actually was going north. And vice-versa. Would it be the clouds? Would it be the high buildings limiting the perspective? To be honest, the same problem happened to me when trying to attend a particular session during the conference: either I met an old friend and started talking (making me late), or all of the sudden I became interested in another topic (switching sessions). Most likely it was me, a little out of focus in my longest absence from home since we had our baby boy, Tomas. But here are my comments…

Having been so involved in the organisation of the previous conference in Barcelona, I knew that this time it was going to be different for me. Interestingly I felt as happy with the things that were retained from the Barcelona edition as with the new features in Vancouver's.

I particularly appreciated the efforts of the organisers to have poster discussions. Although some of them were not well attended or were held too far away from the actual exhibit of the poster, I found it worth keeping them in the future. I really liked having formal discussants in some of the sessions. Just a suggestion for future occasions: that their contribution is more controversial and more directly challenging than the content of the previous presenter.

I loved the Master Lectures. We had them in Baltimore and in Barcelona, but it was not until Vancouver that we found the right title. Also, Vancouver showed us that a brilliant speaker can be placed at the closing ceremony and attract an acceptably large audience.

I was very proud of the continuation of the protocol of the young investigator awards (and the organisers should be congratulated for raising funds for them). People may not realise the coordination efforts necessary to get all the ratings of actual presentations on time (and how much fairer is this than using the abstracts as the basis for the awards). There is still some room for improvement here: we need to provide more information about the awardees and to make sure that they all attend the ceremony (maybe a short CV and a formal commitment could be required when applying).

I am writing this piece a few days after coming back home. And I now realise how nice, dense and lively the city of Vancouver is. My Vancouver memories are so pleasant that I am actually hesitating to send back my Visitor Tax Refund forms…

See you all in Amsterdam!

Congratulations to this year's Young Investigator Award Winners!

Top Oral Presentations:

George Rodrigues, Toronto, Canada

Cheryl A. Moyer, MPH, University of Michigan, Ann Arbor, MI

Top Poster Presentations:

Mina Nishimori, University of Tokyo, Tokyo, Japan

Amy Perwien, University of Florida, Gainesville, FL

A Biased Diary of the ISOQOL 2000 Meeting in Vancouver

Dr. David Osoba
West Vancouver, BC (Canada)

It's only natural that a member of the Scientific Program Committee is likely to have a biased view of the meeting. The direction of the bias will depend on the personality of the diarist, and I'll leave it to you to decide whether I'm an optimist or a pessimist!

For me, the Annual Meeting began long before the 29th of October. Going back to the meeting in Barcelona in November of 1999, I, in a fit of enthusiasm, suggested that the next meeting be held in Vancouver. Until the moment I opened my mouth, from which the unpremeditated invitation issued forth, I had no idea I was going to suggest it. However, after giving it some conscious consideration, I decided that my unconscious mind was right after all and confirmed the invitation.

From there on, there was a series of tasks that needed to be hurriedly undertaken. In my enthusiasm I had momentarily forgotten that my wife and I had long planned a four-month voyage around the world and that, as a result, I would be largely out of contact with the organization until March of 2000. But, a Scientific Program Committee was quickly formed, and my colleagues Diane Fairclough, Carol Moinpour and David Feeny as well as several others stepped in and didn't seem to miss me at all (much to my relief, I may add.) Diane and Laura Degnon (of Degnon Associates, our management company) formed the axis around which all activities revolved. They invented, improvised, copied, improved and implemented the process of putting together the many components of a scientific meeting. We are all extremely grateful to the members of the Committee and to Laura for a highly successful event.

There were several key tasks and events leading up to the meeting itself. One was getting out the notice of the meeting and calling for abstracts.

Another was to find a suitable venue to house the meeting and participants. We decided on plenary session and Master Lectures speakers and discussants. Then, we waited to see if anyone would submit abstracts. Fortunately, over 430 came pouring in. Next, we found willing reviewers and waited for their reviews. Then, we assigned the abstracts to oral and poster sessions, grouping them by topics, and found chairs for the oral sessions and poster discussants. There were discussions with the publisher about publishing the abstracts and an index was devised. Then, we waited for the meeting. Would everyone come? In the week or two before the meeting, we began to receive emails and phone calls from participants who, for a variety of reasons, couldn't come. Oral session chairs inquired about what to do with the gaps that suddenly appeared, like potholes, in their perfectly paved sessions. Rapid last minute consultations with other Committee members resolved such and other issues.

I had a concern during the last two weeks before the meeting about an issue that neither I nor my colleagues could do anything about — the weather! It was remaining warm and sunny during the last two weeks of October and, knowing the West Coast climate, it could not last for long. But would it last at least until the 1st of November? I so hoped that it would remain sunny for the meeting so that the participants could enjoy the natural beauty that Vancouver's setting has to offer. Unfortunately, my worst fears were confirmed. The weather turned nasty on the Friday before the meeting, and you all know the rest. Well, we did get a few sunny breaks. Program Committees may be able to plan a meeting but even they can't do anything about the weather!

On Saturday, the Board met as other participants began to arrive in the city. What a long day that was! (A disadvantage of having the meeting in one's hometown is that you can't sleep in until the last minute and then take the elevator down to the meeting. So it was an early morning awakening for me, but never mind — the sunrise would have been beautiful if it hadn't been windy and raining.) Perhaps few members have a true appreciation of all the matters (some of them complex) that the Board discusses and makes decisions on. Sometimes, apparent impasses lead to frustration, but most of the time I think Board members feel satisfaction with the job they are doing.

The workshops began on Sunday. I had signed up for one in the morning but, instead, found myself cobbling together a press release. We had forgotten to do this earlier! Well, a lesson learned for next year. I did get to the afternoon workshop I had signed up for. The reception in the evening was an exciting event for me. It was the only time when I had a chance to go around and speak to complete strangers and ask them if they were enjoying themselves

On Monday and Tuesday, I participated in many of the scientific sessions, in small part as speaker or chair, partly as listener and partly to "check on how things were going". Were chairs comfortable with their duties? Was the equipment working? A few times, I rescued presenters whose slides would not advance as they should. The fix was easy — a simple matter of aligning the metal plate on the bottom of the carousel with the proper slot. At one point I discovered a paucity of laser pointers. I blamed the hotel personnel until they told me that some speakers were just walking off with the pointers after their presentations. Naughty, naughty!

It was gratifying and reassuring to spontaneously hear form several participants that they thought that the meeting was well organized. I overheard one such comment being made to Diane Fairclough — her grin was as wide as wide could be! Posters appeared on time and in their assigned places; oral sessions went smoothly (with or without pointers); the level of participation was high in most sessions; slide carousels were easily available and the equipment in the "Speakers Ready" room worked; people found the Vancouver Art Gallery for dinner (it wasn't raining) and judging by the verbal noise level, everyone seemed to be having a good time; and we had 475 registrants from 23 countries. This is not to say that the meeting was completely free of glitches. But they seemed relatively few and minor (I warned you that I'm biased!).

One of the most gratifying moments was the presentation of the awards to young investigators. This is one of the most important activities of our society and I hope that the number of awards can be increased substantially in the future to help investigators from all parts of the world to attend.

We are international in scope with representation not only from North America and Europe, but also from Asia, South America, Africa and Australia/ New Zealand. The meeting in Vancouver was a reaffirmation that ISOQOL works and it works well. Yes, there are a lot of oral and poster sessions ahead for many, many years! With the knowledge that the Scientific Program Committee for the meeting next November in Amsterdam is as enthusiastic and committed as was the one for Vancouver, there is no doubt that the meeting in Amsterdam will be a great success!

ISOQOL Pan-Pacific Conference April 13-15, 2001 Tokyo, Japan

Join colleagues for a QOL Conference in Japan.

- March 20, 2001 ~ Early registration deadline

Link to more information through the ISOQOL website at **www.isoqol.org**.

GUEST COLUMN

Editor's Note: *With its roots firmly based in psychosocial, psychometric, and statistical research, the field of quality of life has expanded during the past decades. In this column, quality of life researchers are invited to give their personal views on how the field would further mature. While this is an invitational column, readers with strong views, either supporting or contradicting the opinions voiced by the columnist, are encouraged to react.*

New Directions in HRQL Research

Dr. Rick Berzon
Killingworth, CT (USA)

I design HRQL and other types of outcomes studies as a social scientist for a pharmaceutical company. My interest in patients' perspectives of illnesses and treatments is long standing. For the past 10 years, beginning with my work at the NIH for HIV/AIDS, I have advocated inclusion of HRQL measurement and endpoints in phase II-III clinical trials. While this multidimensional concept has not yet become a regular feature in clinical research, its increased use is well documented. This trend will become more pronounced as the incidence and prevalence of chronic illnesses continue and as cures for chronic diseases become more elusive.

Measurement of patient HRQL now occurs earlier in the clinical research process. This development will continue. There are a variety of health- and business-related reasons for this phenomenon. From a health perspective, HRQL outcomes provide information beyond safety and efficacy and the sooner this information is known, the better for patients, clinical care providers, companies developing new products, and other audiences. In addition, HRQL assessments shed light on the clinical strengths and adverse side effects of drugs, and therefore provide useful profiles for agents under study. These assessments permit agents to be compared in terms of likely patient tolerability and compliance; such findings have important commercial implications for the continued development of the product. It is more efficient if this information can be made available at the end of a phase II clinical study rather than later in the clinical testing process.

Notwithstanding the more routine use of these instruments, HRQL appears infrequently as a primary endpoint. There are several reasons for this current circumstance, although it is unlikely to continue in the future. At present, interpretation of the clinical meaning and significance of HRQL measurement is found by relating and comparing scores to familiar instruments, to other clinical or socially relevant outcomes, and/or to population norms. An effect size, which compares the actual change to variability in baseline scores, and anchor-based interpretations, which compare HRQL scores to clinical changes, are today frequently employed methods. Yet the meaningfulness of HRQL scores has left clinical researchers, particularly physicians, uncertain and unsatisfied. It is understood that more work needs to be done in this area; methods to better analyze and interpret HRQL outcomes continue to be developed and tested.

An issue problematic in the use of a number of primary endpoints in longitudinal clinical studies, HRQL included, relates to missing data. Different types of missing data, which include data missing at random (MAR) and not missing at random (NMAR), and their methods for analyses can profoundly influence trial results. An understanding of how selection of analyses methods may influence the HRQL outcome should precede their selection and subsequent study interpretation. In addition, because imputation of missing data for longitudinal studies is a complex issue, multiple imputation methods are increasingly used in state-of-the-art analyses. In the future, techniques to analyze and impute missing HRQL data are likely to become even more sophisticated; but, regardless of complexity, inclusion of these techniques into the clinical trials process is assured.

While not a new phenomenon, the increasing use of HRQL assessments in routine clinical practice will continue. By extending use of these instruments into this arena, day-to-day clinical decision making will more completely and thoroughly take the patient's perspective into treatment consideration. Patients are demanding this type of information as a consequence of their desire to know, fueled by direct-to-consumer advertisements over the Internet and other modes of communication. Individuals are insisting on having increased responsibility over their health care, and whether information users are ill or well, it is clear that HRQL outcomes add to patient empowerment. This trend is unlikely to dissipate anytime soon.

The topics in this column represent current developments and future challenges for HRQL research; ongoing investigations are more likely to refine existing work rather than break new ground. Nevertheless, funding and research support for this interdisciplinary social science continue to be strong on the part of both the public sector, through agencies such as the Agency for Healthcare Research and Quality, and on the part of the private sector, through pharmaceutical and other technology-based industries. Methodologic rigor and analytic approaches, in addition to significance and meaningfulness of outcomes, will most assuredly characterize future directions within the HRQL field. We all have our work cut out for us!

If you would like to share your reaction to this column, please contact the Newsletter Editor at m.a.sprangers@amc.uva.nl

MEMBERSHIP SURVEY DEMONSTRATES VALUE OF ISOQOL

Dr. Jane Scott-Lennox, Membership Chair
Chapel Hill, NC (USA)

Attendees at the Vancouver meeting were surveyed to learn what about ISOQOL they valued and what member benefits they would like to see added. Of the 475 attendees, 64 returned a completed survey. The limited response cannot be assumed to be an accurate reflection of ISOQOL's full membership but does provide a starting place for discussion about ways the society benefits its members and a number of good suggestions were offered for ways to improve the society. Most (82%) of those who responded to the survey are current ISOQOL members — some have been members since the society was founded in 1994. Roughly three out of four respondents had attended at least one ISOQOL meeting prior to Vancouver.

All those who responded to the survey indicated that advanced notice of meeting and training programs and discounted registration at meetings were valuable benefits of ISOQOL. Most also valued the fact that ISOQOL provides scientific meetings focused on quality of life, opportunities to network with other QOL researchers, and a scientific forum for presenting research.

Respondents suggested other potential membership benefits they would value, as well, including the following:

- Databases of instruments that have been reviewed and approved by an expert panel
- Researchers with shared interests or expertise
- QOL-related courses
- Job opportunities for QOL researchers
- Networking Opportunities

Survey respondents further detailed the many useful networking opportunities ISOQOL can provide:

- Forums to discuss shared interests or debate of controversial HRQL-related issues such as chat rooms and student break out sessions
- More time allotted at meetings to discuss issues; less time for presenting
- List serve of QOL researchers/ members for e-mail discussion and inquiries
- Outreach to clinicians and other research societies interested in health outcomes
- Disease-specific or topic-specific working groups/committees, including subsections by interest area

Members also suggested ways to strengthen participation from researchers in developing countries, enhancements to the ISOQOL website and to the society's journal, ***Quality of Life Research***. Half of the respondents indicated that they would be willing to serve on ISOQOL committees, to review abstracts for future meetings, or for ***Quality of Life Research.***

Although these results offer an encouraging glimpse of the interests and values of ISOQOL's members, they may not represent the full membership of the society. In the future, we hope to improve our response rates to better represent the society's members and to aid in planning benefits and programs that meet members' needs.

NEWS OF MEMBERS

Editor's Note: This column about ISOQOL members will appear as often as there is news worthy of note. Members are encouraged to submit information about new positions, awards, assignments, and memberships of themselves and/or their colleagues.

Erhan Eser MD, of the Dept. of Public Health, Celal Bayar University Faculty of Medicine, Manisa, Turkey has been appointed Associate Professor.

Dr. Mohamed Ibrahim of Malaysia, a QOL Specialist with MAPI Research Institute, is currently working on the development and validation of HRQOL instruments (AQLQ 7 PAQLQ)- Malay and Mandarin language for Malaysia.

Hirohisa Imai MD, PhD has been named assistant professor at the Medical College of Georgia.

Byung Soo Kim, MD, PhD received an award from the International Society of Hematology, Toronto, Canada in August, and is now associate professor in Hemato-Oncology at the Dept. of Internal Medicine, Anam Hospital, Korea University Medical Center.

Cynthia R. King, PhD, NP, RN, FAAN of Rochester, NY gave the Trish Greene Quality of Life Presentation at ONS in front of 1600 nurses on Nov 4 and also was inducted into the American Academy of Nursing on the same day.

In November, **Alex C. Michalos, PhD FRSC**, Professor and Chair of Political Science at the University of Northern British Columbia in Prince George, B.C., Canada, was elected President of the Humanities and Social Sciences Academy of the Royal Society of Canada for a two-year term. The Society, founded in 1882, has three academies containing about five percent of Canadian University teachers, with sixty new Fellows admitted annually.

Kjell Reichenberg, MD wrote: Scientific work of the Nordic School of Public Health, Göteborg, Sweden, which is described at the site www.nhv.se. Colleagues from different countries may contact his group at Allergy@nhv.se to offer initiatives from different scientific fields.

A new book on QOL, edited by **Carolyn Schwartz** and **Mirjam Sprangers**, is in the bookshops. The full reference is: Adaptation to Changing Health. Response Shift In Quality-Of-Life Research. American Psychological Association, Washington: 2000. ISBN: 1-55798-710-6 (hardback, 227 pages, including author/subject index). This volume is the first to examine response shift comprehensively, including the theoretical underpinnings, methodology for assessment in primary and secondary data analysis, and application to treatment outcomes research and medical decision-making. The publication's contributors include the following individuals: Susan Folkman, Lawren Daltroy, Leslie Lenert, Stephen Lepore, Hillary Llewellyn-Thomas, Ciaran O'Boyle, Allen Parducci, Bruce Rapkin, and Ira Wilson.

BIRD'S EYE VIEW: OBSERVATIONS FROM 2000 ANNUAL CONFERENCE ATTENDEES
Vancouver, Canada

Editor's Note: *In the following contributions, four participants of the ISOQOL 2000 meeting were invited to describe the presentations they found particularly revealing, novel, striking, or stimulating.*

New Ideas in Psychometrics "Continually Making the Model Better"

Dr. Ted Ganiats
La Jolla, California (USA)

Like many conferences, ISOQOL offers the opportunity to meet with friends and to share new ideas. Sometimes these new ideas are radical, shaking you to your core. Other times the new ideas build on old thoughts, perhaps thoughts you haven't had for quite some time.

This happened to me as I listened to Peter Fayers' talk entitled, "Over-use and Abuse of Psychometrics—Is There a Role for Clinimetrics?" This talk was important to me for several reasons. First, I see quality of life researchers sitting in two camps (an economic-based utility theory camp and a psychology-based preference camp), but neither camp seems to be entirely correct. Second, Jim Bush, one of the pioneers in our field, once summarized his view of the State of the Art and then concluded, "But remember, this is only a model. Our job is to continually make the model better."

Bush questioned the relevance of much psychometric theory to quality of life research. This is because quality of life is not like the traits evaluated by psychologists, like 'intelligence.' For example, we believe intelligence is constant within any given individual, but we know health-related quality of life changes, often hour to hour.

As a clinician, the basic tenets of psychometric theory (which assumes that a random set of questions about the trait give you insight into the trait) make little sense. In the clinical setting our questions are not random but sequential and directed. All of this points to the limitation of psychometric theory in quality of life research.

Fayers' presentation built on what Bush had taught me many years ago, and pushed our field to continually make our model better by carefully looking at some of our basic precepts. He presented convincing evidence that given much of what we measure in quality of life are "causal variables," many of the standard psychometric tests (correlations, reliability, validity) may be quite misleading.

Exploratory factor analysis, a central piece of much of our work, was deemed "not appropriate" when causal variables are present.

His presentation was clear, and his examples were excellent, but the part of Fayers' talk that most excited me was his stepping back and looking carefully at the construct of quality of life. Doing so, he recognized how fundamentally different it is from much of what economists and psychologists routinely evaluate. This challenges all of us to "continually make the model better."

Factors Affecting HRQL Sessions Important Part of Conference

Dr. Yasmin Maor
Ramat-Gan, Israel

Travelling the long journey from Israel to Vancouver was an excellent decision. I was rewarded with a stimulating conference and beautiful surroundings, thus nurturing both mind and soul. The conference offered excellent research both in the oral presentations and poster sessions. The frustration of having to choose between many interesting parallel sessions was great.

As a clinician, I am struggling to better my understanding of patients' perceptions of their illness, and to learn how to incorporate this information into clinical decision making. Thus, I was particularly intrigued by the sessions devoted to interpretation of health related quality of life (HRQL) scores and to the study of factors affecting HRQL.

One of the illuminating presentations was that of Mathias Rose, where we gained insight into the complex factors influencing HRQL. I learned that in diabetes patients, patients' physical well being is dependent not only on their illness severity but also, on the presence, of an active coping behavior. It seems that physicians role in patients' perception of their HRQL is rather small. This reinforces the idea that perceived physical functioning carries more weight than physical functioning per se and is deeply rooted in mental and cognitive constructs. Getting acquainted with such information is important when designing intervention programs.

Another hot subject is the assessment of clinical significance in HRQL measurement. Many presentations were devoted to this issue, and we could, indeed, appreciate the complexity of this subject. Many presenters advocated anchoring meaningful changes to patients' perspectives. Yet, such incorporation is a delicate matter as we could learn from Neil Aaronson in his presentation regarding the interpretation of clinical changes in the EORTC QLQ-C30 and COOP/WONCA scores. He demonstrated that patients failed to discriminate, retrospectively, between the different functional domains constituting HRQL, and that patients' assessment of change was associated with HRQL scores obtained only in the second take. This raises some concern regarding the validity of transition questions. Another aspect of this complexity was observed in the contributed session chaired by Donald Patrick regarding the interpretation of the effect of Epoetin alfa on HRQL in anemic cancer patients receiving chemotherapy. This was a good chance to see how thorough analysis of data involves many methodological aspects

such as the handling of missing data and defining which items can be pooled from different clinical trials. These issues, as demonstrated, may affect results and should be accounted for. Yet, the basic problem of deciding how and by whom significant clinical changes should be determined remains unresolved. Choosing a criterion derived from laboratory data, such as a change of one gram of hemoglobin, a criterion that both physicians and patients have problems to interpret raises some concern regarding the validity of this choice.

The intellectual challenges that this field offers, both theoretical and methodological, are great, as one could gather from listening to the presentations. The conference provided me with an intellectual challenge for future research and with great expectations to hear the new developments in the next ISOQOL meeting.

A Novel Adaptation of a Simple Idea to Communicate Quality of Life Results — Simple is Better

Dr. David Himmelberger
Palo Alto, California (USA)

An area where quality of life research still has problems is communicating findings to audiences who are not well trained in statistical methodology. Many of the presentations at the recent ISOQOL meeting in Vancouver advanced the scientific rigor of the field, although the increasingly complex methodologies often tend to obscure, rather than clarify the significance of the findings.

Pamela Atherton and her colleagues at the Mayo clinic resurrected an old idea of the event chart to communicate quality of life results. The basic visual display of event data shown as colored bars as a function of time is easy to understand.

Rather than merely generating scatter plots, event charts of *clinically significant* or *meaningful* changes provide a visual display that can effectively communicate multiple types of data in a simple form. An effective application of the event chart method provided by Atherton was to the standard Kaplan-Meier (K-M) step function of survival data. Rather than examining multiple K-M plots for intermediate events, such as stage 1, stage 2 and death, the event chart display provides a single visual display of all the information with different colored bars for the different events.

The event chart method has the advantages of being able to easily track individual patients, identify emerging transition patterns and display frequency, intensity and duration on a single plot. The drawbacks are that it requires one to make arbitrary definitions of events and yields a qualitative result with no standard for comparison.

Atherton and her colleagues should be commended for their insight in reviving a simple way to communicate quality of life results to the non-statistically trained audience. One challenge that remains is to determine which colors most effectively communicate the outcome.

Further information can be obtained by contacting Pamela Atherton at atherton@mayo.edu.

Quality of Life in Children and Adolescents Research: "Growing Up" at the ISOQOL Convention

Dr. Ulrike Ravens-Sieberer, Ute Ellert, Susanne Bettge
Berlin, Germany

Coming from the field of quality of life research in children and adolescents, we were very enthusiastic to see so many abstracts, sessions and presentations concerning this topic at this year's ISOQOL-Conference in Vancouver. The program of the conference included a master lecture, an oral session with five oral presentations covering a broad range of topics in the child quality of life field, fourteen posters and a poster discussion session in which four posters were presented in more detail.

The master lecture on assessing quality of life in children and adolescents with a chair and three panelists was very well attended. The session chair, David Feeny, introduced a list of six key issues covering the main research topics on assessing quality of life in children and adolescents. Each panelist was given a period of 10 minutes to make initial remarks, and this was followed by a discussion among those attending the session and the members of the panel.

Discussing the main topics of quality of life research in children and the six key issues, it became clear that the field of quality of life assessment in children has moved from designing instruments to a period in which those instruments are increasingly being implemented in clinical and epidemiological quality of life studies. The six key issues covered were: a) the statement that appropriate measures are currently available, b) proxy assessment versus self-assessment, c) accumulating evidence and identifying gaps, d) the challenge of developing measures for preschool children, e) the challenge of interpreting quality of life scores from instruments in the child field, and f) the challenge of demonstrating the usefulness of assessing health-related quality of life of children and adolescents in clinical studies.

The audience of the children's panel session agreed that the topic of children should receive broader attention in the general field of quality of life research and that the research strategies in the children's field have become more "grown up" over the past years. There was a strong consensus that, last but not least, clinicians should be encouraged to include quality of life measures in their day-to-day practice, in treating individual patients and in monitoring medical care. Instruments have already been implemented in institutions such as hospitals or rehabilitation clinics, as well as out-patient services. The challenge faced by the quality of life field is the issue of attaching meaning to a given score and of clarifying what it means in such terms that can be understood by the circle of users: clinicians, families and policy makers. This is a skill that needs to be developed and expanded in the future.

ISOQOL Conference: November 7-10, 2001
Amsterdam, The Netherlands

Important 2001
Annual Meeting Dates:

- January 22, 2001 ~ Call for Abstracts
- May 1, 2001 ~ Abstracts Due
- June 30, 2001 ~ Notification Sent about Abstracts
- July 30, 2001 ~ Presenter Confirmation Due; Early Registration Deadline

Invited Speakers, Workshops, Papers & Posters

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Scholarship Applications are available. Please contact the ISOQOL office for information: *info@isoqol.org*

ISOQOL would like to thank the following companies for their generous support of this year's Annual Meeting in Vancouver:

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Pfizer
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QualityMetric
Roche
RTI Health Solutions
Smith Kline
Wyeth-Ayerst

CALENDAR OF EVENTS

- **ISOQOL Methods Workshops**, Feb. 5-6, 2001, Washington, DC
- **Fatigue und Krebs II / Fatigue and Cancer II**, Feb. 16-17, 2001, Cologne, Germany
- **ISOQOL Pan-Pacific Conference**, April 13-15, 2001, Tokyo, Japan
- **6th Annual ISPOR Conference**, May 20-23, 2001, Arlington Virginia, USA. Abstract Deadline: January 12, 2001 Registration Deadline: May 1, 2001
- **REVES 13th Annual International Meeting**, June 28-30, 2001, Vancouver, BC, Canada Abstract Deadline: Jan. 31, 2001 Registration Deadline: May 1, 2001
- **ISOQOL 8th Annual Conference**, Nov. 7-10, 2001, Amsterdam, The Netherlands.

ISOQOL Executive Office
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POSITIONS AVAILABLE

Robert Koch Institute, Berlin, Germany: is searching for individuals for two research projects about QoL in children and adolescents. E-mail Ulrike Ravens-Sieberer, PhD, MPH at Ravens-SiebererU@rki.de for a full description.

The University of Cincinnati Medical Center and the Cincinnati Veterans Affairs Hospital seek MDs or PhDs with clinical research training and experience in outcomes research, health decision sciences, clinical epidemiology, health services research, or clinical practice improvement. Contact Joel Tsevat, MD, MPH at Joel.Tsevat@UC.Edu.

The Department of Pharmaceutical Economics and Policy, University of Southern California offers a 12-month tenure track position for an individual with expertise in health economics, econometrics, health services research or related field. For more information, contact Denise Globe, PhD at globe@usc.edu.

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